

## **COMMENT**

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## The Nuffield report on genome editing and the equality of persons

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lot of hard work was invested into the UK's Nuffield Council on Bioethics' new, pioneering, report entitled 'Genome Editing and Human Reproduction: Social and ethical issues'. But a lot more work is still necessary to gain an appropriate overview of heritable genome editing since a number of ethical arguments are missing from the report, while others are insufficiently developed. As a result, the report cannot be seen as safe when it indicates that it 'can... envisage circumstances in which heritable genome editing interventions should be permitted'.

For example, the report does not sufficiently investigate the way such procedures may undermine the absolute equality in value and worth of all persons in civilised society.

One way to do this is to first consider the synecdoche argument: this examines whether it is possible or appropriate to reduce a whole, such as a person, to just a part or trait, such as a disorder. This is because, in the reproductive setting, disorders cannot be considered on their own without being embodied in persons. It is always a possible future person, or a real existing person, with or without a disorder who should be considered and not just the disorder by itself.

Secondly, the non-identity argument is very relevant though, admittedly, this was briefly mentioned in the report. This implies that there is a crucial philosophical difference between changing a trait, such as a disability, in a person who exists and making sure that a person with such a trait does not come into existence.

Together with the synecdoche argument, this means that many individuals who were brought into existence, from the very beginning, with a disability may consider this condition as an existential part of their very identity. This is in contrast to individuals who may have become disabled later in life who may not associate their very existence with this condition.

Finally, the <u>expressivist argument</u> should be considered. This argument is often presented as the concern that preventing the very existence of certain individuals with specific disabilities is an expression of disvalue for existing people with the disabilities.

Again, this argument was noted in the report but was, unfortunately, not developed in a manner which presented all its many different and important articulations. This would then have addressed the shortcomings of the report relating to this expressivist argument when it ignored the synecdoche argument while noting that 'it is

possible to disvalue a condition that gives rise to disability at the same time as valuing people who have the condition as highly as those who do not'.

Taking a closer look at this statement in the report, however, a number of important questions can be asked

The Nuffield report on genome editing and the equality of persons - Richlews at the way individuals, such as prospective parents, can make a choice between possible future children. For cample:

- Are these individuals stating that possible future children are actually unequal in value and worth?
- How is this choice being made? Moreover, since no real deliberate decision ever takes place without being informed by the real world, are these individuals considering certain possible future lives by projecting them into reality in order to decide which ones should come into existence? Furthermore, are they basing their choice on their experiences and perceptions of children, who already exist?
- Are these individuals basing their decision solely on quality-of-life arguments? And, if so, what other moral
  arguments are they using, subsequently, in the real world of existing individuals in order to believe that
  everyone is absolutely equal in value and worth? Moreover, why and how do these new arguments only
  apply once persons actually exist?

It is regrettable that the report does not address these questions. The decision that individuals or a society makes between possible children are often talked about in the context of imagined future persons. But the decision itself is one with real consequences, not in an imagined world but in this world. Those consequences include the reality that only certain children are being brought into existence. Indeed, it is difficult to see how a real and genuine expression of the actual moral values of these individuals or that of a society in the real world is not being revealed.

Accepting heritable genome editing and the possibility of choosing between different kinds of future children, therefore, may become an outward expression of the moral values of a person or a society in the real existing world. Values that accept an inequality in the inherent worth of existing, and very real, people.

An important safeguard in the report is its proposed principle of 'social justice and solidarity'. This states that genome editing procedures 'should be permitted only in circumstances in which it cannot reasonably be expected to produce or exacerbate social division or the unmitigated marginalisation or disadvantage of groups within society'.

On this account, however, and based on the above dangers to the absolute equality of value and worth of all persons in a civilised society, it is impossible to see any occasion when heritable genome editing could ever be acceptable or permitted by legislation. Indeed, a compassionate civilised society is one that offers unconditional acceptance of the deeply suffering, as well as the deeply contented child. It is one that learns to welcome all possible future children as equally valuable.

Note: The views expressed in this article are those of the author and do not necessarily reflect the positions of the professional organisations with which he is affiliated.

## **SOURCES & REFERENCES**

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